


## Review Article

# Integrated Care in Neurology: The Current Landscape and Future Directions

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**ABSTRACT:** The rising burden of neurological disorders poses significant challenges to healthcare systems worldwide. There has been an increasing momentum to apply integrated approaches to the management of several chronic illnesses in order to address systemic healthcare challenges and improve the quality of care for patients. The aim of this paper is to provide a narrative review of the current landscape of integrated care in neurology. We identified a growing body of research from countries around the world applying a variety of integrated care models to the treatment of common neurological conditions. Based on our findings, we discuss opportunities for further study in this area. Finally, we discuss the future of integrated care in Canada, including unique geographic, historical, and economic considerations, and the role that integrated care may play in addressing challenges we face in our current healthcare system.

**RÉSUMÉ :** Soins intégrés en neurologie : paysage actuel et orientations futures. Le fardeau croissant que représentent les troubles neurologiques pose des défis importants aux systèmes de santé du monde entier. À cet égard, on a pu noter un élan croissant pour adopter des approches intégrées en matière de gestion de nombreuses maladies chroniques, et ce, afin de faire face aux défis systémiques des soins de santé et d'améliorer la qualité des soins prodigués aux patients. L'objectif de cet article est donc de fournir une analyse narrative du paysage actuel des soins intégrés en neurologie. Pour cela, nous avons identifié un nombre croissant de recherches menées dans des pays du monde entier qui mettaient de l'avant divers modèles de soins intégrés dans le traitement de maladies neurologiques courantes. Sur la base de nos résultats, nous entendons aborder les possibilités d'études supplémentaires dans ce domaine. Enfin, nous souhaitons discuter de l'avenir des soins intégrés au Canada, y compris des considérations géographiques et économiques uniques, ainsi que du rôle que les soins intégrés peuvent jouer pour relever plusieurs défis auxquels nous sommes confrontés dans notre système de santé actuel.

**Keywords:** collaborative care; dementia; epilepsy; headache; integrated care; multiple sclerosis; Parkinson's disease; stroke; traumatic brain injury

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## Introduction

The rising clinical, social and economic impact of non-communicable neurological disorders poses significant challenges to healthcare systems worldwide.<sup>1</sup> Tator *et al.* found that six neurological disorders – Alzheimer's disease, Parkinson's disease (PD), multiple sclerosis (MS), stroke, epilepsy and headache – altogether accounted for one in ten of the total disability-adjusted life years for all illnesses in Canada.<sup>2</sup> Furthermore, the incidences of many common neurological conditions, including Alzheimer's disease and PD, are expected to continue to increase in the following decades as our population ages.<sup>3</sup> It has been demonstrated that patients with neurological illnesses have greater healthcare needs than those without, including more specialist appointments, emergency departments visits, and overnight hospitalizations.<sup>3,4</sup> The complexity of their care is further

compounded by inefficiencies in our healthcare systems, such as the fragmentation of resources within local communities and the heterogeneity of electronic medical records systems across clinics and hospitals,<sup>5,6</sup> to name a few, leading to higher healthcare costs and worse outcomes for patients.<sup>7,8</sup> Altogether, these factors contribute to growing healthcare expenses as well as indirect economic costs due to premature death and disability.<sup>3</sup> Simultaneously, there is increasing recognition that our understanding of these diseases viewed in isolation from the complex systems in which we exist is incomplete, as a growing body of research underscores the impact of the social determinants of neurological health.<sup>9</sup>

In recent years, there has been an increasing momentum globally to apply integrated approaches to the management of chronic illnesses in order to address systemic healthcare challenges and improve the quality of care for patients and populations.<sup>10</sup> As

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defined by the WHO Regional Office for Europe: “*Integrated health services delivery is defined as an approach to strengthen people-centered health systems through the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. It should be effectively managed to ensure optimal outcomes and the appropriate use of resources based on the best available evidence, with feedback loops to continuously improve performance and to tackle upstream causes of ill health and to promote well-being through intersectoral and multisectoral actions.*”<sup>11</sup> In contrast to traditional models of multidisciplinary care, integrated care aims to meet the needs of both people and populations through multiple dimensions of integration, including between healthcare providers, services, organizations and systems, to provide comprehensive, coordinated, continuous, collaborative and cost-effective care that is simultaneously person-focused, with the expectation of active participation from the patient and/or care partner, and population-based, with an emphasis on the just use of resources.<sup>12</sup>

The Rainbow Model developed by Valentijn and colleagues conceptualizes integration at various levels of care, while simultaneously highlighting the need to tailor care to patients’ needs and values.<sup>12</sup> These authors defined system integration as integration across levels of care; for example, between primary, secondary and tertiary care. In their model, *organizational integration* involves the coordination of the delivery of services, which can be achieved by the creation of regional health networks with common governance mechanisms and a collective responsibility for the health and well-being of a defined population. *Professional integration* is defined as partnerships between professionals to promote shared accountability, problem-solving and decision-making, which includes interdisciplinary care teams as well as collaboration between different organizations, such as between the patients’ specialty team and their family physician. *Clinical integration* focuses on the coordination of care delivery “across time, place and discipline”, with emphasis on the patient taking an active role in their own care. For example, many integrated care models are based on care navigation, a concept with roots in oncology in the late 20<sup>th</sup> century,<sup>13</sup> and which typically relies on specialized nurses to support the self-management of patients and caregivers and connect them to appropriate services throughout the course of their illness. *Functional integration* involves the integration of non-clinical support and back-office functions, an important example of which is the standardization of electronic medical records, which can help streamline communication and shared care. Finally, these authors highlight the importance of *normative integration*, which represents “the shared mission, vision, values and culture between organizations, professional groups and individuals”. The Rainbow Model of Integrated Care Measurement Tool (RMIC-MT) has subsequently been developed and validated to measure care integration within various healthcare systems, with both a patient and a care provider version available.<sup>14–19</sup>

The applications of integrated approaches have been rapidly expanding to a variety of areas including primary care and geriatric medicine,<sup>20,21</sup> as well as disease-specific models.<sup>22</sup> Jaglal and colleagues elaborate on the Expanded Chronic Care Model<sup>23</sup> and highlight the need for specific considerations in the development of integrated approaches for neurological conditions, such as addressing the needs of caregivers and supporting transitions to

higher levels of care with disease progression.<sup>24</sup> In recent years, there have been growing efforts to apply integrated approaches to address the rising burden that neurological diseases place on patients and families, healthcare systems and communities.

Therefore, the aims of the current paper are to:

1. Provide a narrative review of the current landscape of integrated care in neurology; and
2. Discuss how integrated care may help address challenges in our current Canadian healthcare system.

## Methods

For our narrative review, a search of the published literature available on PubMed was initially conducted in November 2022. This was repeated in August 2023 and November 2023 to capture new articles. Our keywords were refined based on relevant results from previous searches, therefore the most recent search was performed using a combination of “neurology” and “integrated care” or the following related keywords: “integrated health,” “integrated approach,” “user-led,” “chronic care model,” “Rainbow model,” “coordinated care,” “seamless care,” “transmural care,” “comprehensive care,” or “collaborative care.” This resulted in a total of 685 articles. Additional articles were identified through citation mining and through the “Similar Articles” and “Cited By” features on PubMed. The articles were subject to the following inclusion criteria:

1. The article was written in the English language.
2. The article detailed a model of integrated care aligning with commonly-accepted definitions, such as those put forward by the WHO Regional Office for Europe<sup>11</sup> and Valentijn and colleagues,<sup>12</sup> namely, focusing on the provision of person-centered care involving interdisciplinary collaboration and the coordination across services or levels of care.
3. The article discussed the application of integrated care to the chronic, comprehensive medical management of a neurological disorder in the adult population.

A total of 15 care models ultimately met all inclusion criteria (Table 1).

## Disease-specific models of integrated care in neurology

### Parkinson’s disease (PD)

In recent years, PD nurse specialists have taken on an invaluable role in the comprehensive care of patients with PD,<sup>40</sup> especially in the United Kingdom, and are fundamental to several models of integrated care captured in our review.

For example, several groups have described conceptual models of integrated care for PD centered around care management provided by nurse specialists and also bring attention to the potential benefits of technology-enabled care, such as those that promote remote health monitoring and self-management support, as well as electronic medical records. Bloem *et al.* illustrate a comprehensive integrated care concept for patients with PD based on a “home-hub-and-spoke” model.<sup>26</sup> In this model, the patient’s home represents the promotion of patient empowerment and self-management, including home-based monitoring. The “spoke” encompasses the clinical care provided by movement disorder specialists and allied health professionals in the local community, coordinated by a nurse specialist. Finally, the academic “hub”

**Table 1.** Summary of articles on integrated care models in neurology

Name of Model	Author/Year of Publication	Country	Disease Focus	Study Design	Project Funding
Integrated Parkinson Care Network	Mestre <i>et al.</i> 2021 <sup>25</sup>	Canada	PD	Prospective pre-post design	Physicians' Services Incorporated Foundation, Parkinson Research Consortium, University of Ottawa
N/A	Bloem <i>et al.</i> 2020 <sup>26</sup>	N/A	PD	Proposed framework	N/A
iCARE-PD	Fabbri <i>et al.</i> 2020 <sup>27</sup>	N/A	PD	Proposed framework	N/A
Parkinson Network Eastern Saxony	Loewenbrück <i>et al.</i> 2020 <sup>28</sup>	Germany	PD	Proposed framework	German government, tax funds
PRIME-Parkinson	Tenison <i>et al.</i> 2020 <sup>29</sup> ; Lithander <i>et al.</i> 2023 <sup>30</sup>	N/A	PD	Proposed framework	Gatsby Foundation, Ministry of Economic Affairs (nation not specified)
Cologne Parkinson Network	Eggers <i>et al.</i> 2018 <sup>31</sup>	Germany	PD	RCT	Abbott Pharm, Archimedes, Bayer Vital, Medtronic, Teva Pharma, UCB Pharma, Zur Rose Pharma
Comprehensive Memory Center	Aguirre <i>et al.</i> 2023 <sup>32</sup>	USA	Dementia	Program evaluation	Medicare
Dementia Care Partners	Goldfarb <i>et al.</i> 2022 <sup>33</sup>	USA	Dementia	Program evaluation	Medicare, private donors, Cigna grant, Banner Alzheimer's Foundation, Banner Health Foundation, Sun Health Foundation
Integrated Memory Care Clinic	Clevenger <i>et al.</i> 2018 <sup>34</sup>	USA	Dementia	Program evaluation	Medicare, private donors
Center for Cognitive Neurology & Alzheimer Disease Center	Galvin <i>et al.</i> 2014 <sup>35</sup>	USA	Dementia	Program evaluation	Medicare, National Institutes of Health grant, New York State Department of Health, Morris and Alma Schapiro Fund
Integrated Care for the Reduction of Secondary Stroke (ICARUSS)	Joubert <i>et al.</i> 2020 <sup>36</sup>	Australia	Stroke	RCT	HCF Research Foundation
MS Care	Ehde <i>et al.</i> 2018 <sup>37</sup>	USA	MS	Study protocol for RCT	Patient-Centered Outcomes Research Institute
Danish Headache Centre	Jensen <i>et al.</i> 2010 <sup>38</sup>	Denmark	Headache	Program evaluation	Danish healthcare system
Ireland's National Clinical Programme	2016	Ireland	Epilepsy	Program description	Health Service Executive (Ireland's public healthcare system)
N/A	Li <i>et al.</i> 2021 <sup>39</sup>	UK	TBI	Proposed framework	N/A

PD = Parkinson's disease; MS = multiple sclerosis; TBI = traumatic brain injury; RCT = randomized controlled trial.

augments the entire network by providing support for community neurologists, developing guidelines, and conducting research.

In recent years, iCARE-PD, an international consortium of PD researchers, health economists, sociologists, ethical and legal experts and policymakers, has emerged to promote the development of integrated care networks, based on a model co-designed with patients, care partners, and healthcare providers.<sup>27,41,42</sup> Their model focuses on home-based community-centered care with three core pillars: 1. *Integrated care*, such as through integrated care teams and community resources, and care coordination by specialized PD nurses; 2. *Self-management*, through patient and care partner education and supported by the PD nurse; and 3. *Technology-enabled care*, including telemedicine and interactive health monitoring.

The PRIME-Parkinson model (Proactive and Integrated Management and Empowerment in Parkinson's Disease), developed by researchers from the UK and the Netherlands, also brings attention to the potential benefits of technology-enabled care and

was developed with the following aims: 1. *Personalized care management based on shared decision-making provided by a PD nurse*; 2. *Education and empowerment of patients and carers targeted to specific disease stages*; 3. *Empowerment of healthcare professionals through updated guidelines, tools, protocols and an online collaboration platform*; 4. *A population health approach with the coordination of care services within defined regions*; and 5. *Patient- and professional-friendly technology to facilitate communication and collaboration*.<sup>29</sup> A randomized controlled trial applying their model is currently underway, with the primary outcomes of attainment of personalized goals and care-related quality of life for patients and caregivers, respectively.<sup>30</sup>

In Germany, several integrated care networks have been established for patients with PD and atypical parkinsonian disorders.<sup>43</sup> As an example, Loewenbrück *et al.* describe the development of the Parkinson Network Eastern Saxony (PANOS) by a team consisting of community-based physicians, PD specialists, allied health professionals, patients and representatives

from statutory health insurance and local medical authorities.<sup>28</sup> This care initiative is centered around intersectoral case management to promote continuity and collaboration between specialists and general practitioners, the development of individualized care plans, the promotion of self-monitoring and self-management strategies, and a centralized electronic health record accessible to all healthcare providers in the network. While the roles of other healthcare providers such as physiotherapists are not currently integrated into the network, this is a stated aim for later implementation phases. Their paper also details the pragmatic considerations of their initiative, including challenges in finding consensus on reimbursement models for the clinicians involved.

Mestre and colleagues from the University of Ottawa developed the Integrated Parkinson Care Network (IPCN) based on the Expanded Chronic Care Model, which was co-designed with patients with PD and their caregivers.<sup>25,44</sup> The model is primarily carried out by specialized PD nurses and focuses on patient education, self-management support, shared decision-making, and structured follow-up. Furthermore, their program involves the linking of existing resources based out of community and tertiary settings to help facilitate care navigation. A 6-month phase 2 study demonstrated that personalized care priorities were met in over 90% of cases, with statistically significant improvements in health-related quality of life for patients with advanced disease as measured by the Parkinson's Disease Questionnaire (PDQ-8) and high patient satisfaction. Furthermore, the authors estimated a high return of investment, with a \$4.08 gain for each \$1 invested through reductions in societal costs.

The Cologne Parkinson Network based in Germany, formed by a movement disorders specialist, community-based neurologists, and a PD nurse, demonstrated promising results in a randomized controlled trial of their model of integrated care for PD.<sup>31</sup> In addition to standard care provided by community neurologists, patients received individualized treatment plans from nurse specialists who were also responsible for home visits and care coordination more broadly. In a randomized controlled trial, the model demonstrated significant improvements in quality of life as measured by the Parkinson's Disease Questionnaire (PDQ-39), motor symptoms as assessed in the Unified Parkinson's Disease Rating Scale (UPDRS) Part III and the PD Non-Motor Symptoms (NMS) questionnaire.

## Dementia

Clevenger and colleagues established the Integrated Memory Care Clinic at Emory University, where advanced practice registered nurses (APRN) take the lead as first-line clinicians, working closely with nurses, social workers and patient care coordinators, and collaborating with a neurologist and geriatrician as needed.<sup>34</sup> Once they are connected to the clinic, individuals with a variety of dementia subtypes or mild cognitive impairment (MCI) transfer their primary care to the clinic completely and the team develops comprehensive individualized care plans in conjunction with patients and caregivers. The clinic aims to decrease unnecessary burden on the healthcare system, for example by discussing care goals with families to reduce inappropriate diagnostic procedures and having an on-call APRN that families can contact prior to presenting to the emergency department. In their first year of operation, they demonstrated reductions in emergency department visits and hospital admissions, as well as nonsignificant reductions in neuropsychiatric symptom severity and associated

caregiver distress, and nonsignificant improvements in caregiver competence.

In a similar fashion, Goldfarb *et al.* detail the development of a pilot Dementia Care Partners program within a nonprofit community health system organization in the United States for patients with MCI or dementia. This model centers around Health Coaches, unlicensed support providers with specific training in dementia, who function as the main point of contact between patient-caregiver dyad, the multidisciplinary dementia team, and the patients' primary healthcare providers.<sup>33</sup> The Health Coaches work closely with patients and caregivers to perform clinical assessments and develop personalized care plans, and the pilot program demonstrated feasibility and high caregiver and primary care provider satisfaction.

In contrast, Galvin and colleagues from New York University describe a collaborative care model for MCI and dementia in which the physician, nurse practitioner and social worker perform their assessments simultaneously prior to meeting with the patient and caregiver as a team for a comprehensive care conference to develop a personalized care plan.<sup>35</sup> Evaluations of the program demonstrated improvements in patient- and caregiver-centered outcomes including increased disease knowledge and a greater sense of control, and overall high satisfaction with the program.

Aguirre and *et al.* similarly co-designed the Comprehensive Memory Clinic at the University of Texas in Austin in conjunction with patients and caregivers, which includes a behavioural neurologist, a general neurologist, a geriatric psychiatrist, neuropsychologists, a nurse practitioner, a registered nurse, social workers, speech-language pathologists, a pharmacist and psychometrists.<sup>32</sup> Clinic visits can be structured as team visits at which several members of the team are simultaneously present. Care plans are discussed at weekly team meetings and developed in conjunction with patient and caregiver goals. Feedback on care plans are solicited from patients and caregivers prior to finalization, and these are then also shared with their primary care physicians. In addition, the clinic collaborates closely with community-based organizations and research groups to make relevant information available to patients and caregivers through monthly presentations and a resource library. Their program demonstrated an average two-month interval between the initial appointment to the time of diagnosis, compared to an average of 14.8 months based on existing literature,<sup>45</sup> as well as high patient, caregiver and staff satisfaction.

## Stroke

While we recognize that there has been much work highlighting the importance of multidisciplinary stroke units for acute stroke care and inpatient rehabilitation,<sup>46</sup> we feel that the traditional multidisciplinary model of early post-stroke care typically focuses on a short-term care intervention, without discussion of bridging of patients' care to the chronic care period, such as through collaboration with their primary physician or the coordination of community resources to provide ongoing support.<sup>47-55</sup> Consequently, we feel that these many of these studies do not meet the contemporary criteria<sup>11,12</sup> for integrated care, particularly as it pertains to systems integration and providing longitudinal stroke care.

In contrast, Joubert and colleagues established the Integrated Care for the Reduction of Secondary Stroke (ICARUSS) model for risk factor management in recent stroke survivors by utilizing a



care coordination approach.<sup>36</sup> Their intervention, assessed in a multicenter randomized controlled trial in hospitals across Australia, begins in the inpatient setting, involving the development of a personalized care plan for each patient, education around stroke and tools for self-management. After discharge, patients receive regular follow-up with a care coordinator who serves as the point of contact between patients and caregivers, their primary care physicians and the stroke specialists. In addition, there was clear communication of the care plan to the primary care providers, as well as between the primary care providers and the stroke specialists as needed. In a randomized controlled trial, they demonstrated significant improvements in systolic blood pressure, total cholesterol and triglyceride levels, exercise tolerance and decreased alcohol consumption in the intervention group compared to controls.

### Multiple sclerosis (MS)

The MS Care Trial is a 16-week randomized controlled trial at the University of Washington investigating a collaborative model to improve the care of chronic pain and depression for patients with MS.<sup>37</sup> The model was designed in a participatory manner with patients with MS, their families, advocacy groups and MS clinic providers. In addition to their usual care, patients randomized to the intervention arm of the trial are followed closely by a MS Care Manager, a social worker with specialized MS training, who works directly with patients while representing the treatment recommendations of an interdisciplinary team who meet weekly, including the treating MS physician, a psychologist, a psychiatrist and a pain expert. The MS Care Manager collaborates with the patient to develop a personalized treatment plan, performs regular symptom assessments, reviews adherence to pharmacological and non-pharmacological strategies, and promotes patient self-management by providing education and brief behavioral treatments. The trial is currently in progress, with the primary outcomes being the control of pain and depressive symptoms.

### Headache

The Danish Headache Center is an integrated, multidisciplinary headache clinic where patients initially meet with a neurologist who, in conjunction with the patient, develops a treatment plan including patient education and self-management strategies, medical therapies and referrals to the clinic's physical therapists, psychologist and/or nurses as needed.<sup>38</sup> Additionally, the clinic has specialized nurses to provide close follow-up and support for patients with medication overuse headaches, which may involve enrollment in a group outpatient program or a two-week inpatient program. The clinic has also developed structured relationships with other hospital departments and specialties including neurosurgery, psychiatry, anesthesiology, gynecology and dentistry. They demonstrated significant positive results over a two-year period, as the average frequency of headaches were reduced from 20 to 11 days per month and sick days from work were reduced five to two days per month on average. For an excellent review of other integrated care models for the management of headache, we recommend the 2011 review article by Diener *et al.*<sup>56</sup>

### Epilepsy

Ireland has introduced several National Clinical Programmes (NCPs) which are integrated disease-specific models of care with services coordinated across the country.<sup>57</sup> As an example, the NCP

for Epilepsy was introduced in 2016 to transform the provision of epilepsy care across the country.<sup>58</sup> The program focuses on the vertical integration (i.e. across primary, secondary and tertiary care) of services nationally, and a major component of this program is the establishment of Group Based Epilepsy Centers, a nurse-led model in which registered advanced nurse practitioners (RANPs) work closely with neurologists, epilepsy specialists and general practitioners to provide routine outpatient epilepsy care, with an emphasis on patient self-management. In addition, the role of the RANPs also encompasses providing telehealth advice, rapid access services for community and emergency department referrals, consultation for patients in acute care settings, and outreach to other healthcare institutions. Key performance indicators include reductions in clinic wait times, hospital admissions and length of stay, although publicly-available data on the early implementation of the program is not currently available.

### Traumatic brain injury (TBI)

Li and colleagues proposed an integrated healthcare pathway within the National Health Service (NHS) in the United Kingdom for patients following TBI, in which dedicated interdisciplinary teams follow patients from the acute care setting at centralized trauma centers, to early rehabilitation and then into the community, with a focus on comprehensive, personalized and longitudinal care.<sup>39</sup> Central to their model is the role of the neuro-navigator, similar to that of a case manager, who supports the patient's transition from hospital to community and helps to connect the patient with appropriate services based on their unique needs. The authors suggest that their care pathway may be associated with significant cost savings, citing pilot implementation at one hospital which demonstrated a 37% reduction in inpatient stay duration and £30,000 in cost savings.

### Discussion

In this narrative review, we found a growing body of research applying a variety of integrated care models to the treatment of common neurological conditions, spanning Parkinson's disease, dementia, stroke, MS, headache, epilepsy and TBI. These models originated in several countries across North America, Europe and Australia, and differ in their reach, from independent clinics to regional and international initiatives. We acknowledge that as the aim of this paper was to provide a narrative review of work in integrated care relevant to neurology, this does not serve as a systematic review of the literature to capture the entire body of work in this area. However, by summarizing the current state of research on integrated care in neurology, we do identify several gaps in the literature that strongly warrant further study.

### Standardized definitions of integrated care

Several groups have previously highlighted the heterogenous definitions of healthcare systems integration<sup>59</sup> and indeed, despite calls for a unified definition of integrated care,<sup>11</sup> we observed inconsistent applications of the terminology during our literature search.<sup>60</sup> Other groups, as reviewed by Rajan and colleagues,<sup>61</sup> have applied different definitions to integrated care that we feel is more aligned with traditional multidisciplinary care as they do not include all components that may be implicit in more comprehensive definitions, such as a focus on the active participation of the patient in their care and an emphasis on broader systems

change, suggesting that the translation of these conceptual elements into clinical infrastructure requires further exploration. It is crucial that we apply these terms in a precise manner and in accordance with standardized definitions<sup>11,12</sup> in order to successfully shift the paradigm of future healthcare delivery.

### Representation across neurological disorders

Not all neurological conditions are represented equally in our sample, and we note that the majority of these models are clinician- and researcher-driven, which may influence the distribution of initiatives across the spectrum of neurological disease. We found a scarcity of integrated care programs developed for neuro-oncology patients, despite several calls for the need for longitudinal, coordinated and patient-centered care for these patients and their caregivers.<sup>62,63</sup> Although experience may be borrowed from the broader oncology sphere, Pace and colleagues identify several unique aspects of neuro-oncological disease that require special consideration, including psychiatric symptoms and caregiver needs.<sup>63</sup> Also, while we acknowledge previous efforts to advance multidisciplinary care for patients with motor neuron disease<sup>64</sup> and Huntington disease,<sup>65,66</sup> we hope to see the emergence of truly integrated approaches in the care of these patients in coming years.<sup>67,68</sup>

We acknowledge, however, that an important limitation of our current review is that the aim was to summarize integrated care models documented in the published body of literature. Moving forward, consideration of alternative data-gathering strategies, such as through surveying clinicians at various institutions, may better serve to capture additional integrated care models outside of the academic literature.

### Alignment of patient and provider expectations

We believe that the goal of aligning patient and provider expectations should lie at the core of integrated care.<sup>69</sup> For instance, Clevenger and colleagues illustrated the importance of iterative conversations to align caregivers' and healthcare providers' views on appropriate medical interventions for the patient's clinical status in order to ensure the thoughtful use of resources and minimize harms to the patient.<sup>34</sup> While several other papers did highlight the importance of eliciting patient goals for their care, it was less clear how they addressed the aspect of aligning expectations. Andersen's Behavioral Model of Health Services Use identifies three factors that influence health services use for an individual, namely: 1. *Predisposing factors*; 2. *Enabling factors*; and 3. *Need factors*.<sup>70,71</sup> Using this model as a framework, we hope that integrated care models can better align patients' *perceived need* for services with providers' *evaluated need* in order to reduce unnecessary healthcare costs while simultaneously increasing patients' sense of agency and satisfaction in their care.<sup>72,73</sup> Furthermore, patient expectations have been demonstrated to have significant effects on functional outcomes,<sup>74</sup> although the strength and direction of this relationship appears to vary by disease and intervention. Moving forward, it is critical to assess the extent to which integrated care models meet the needs of patients, both in a quantitative manner by applying validated tools,<sup>75</sup> and by utilizing qualitative methods to illustrate patient experiences.<sup>76</sup>

### Assessment with validated outcome measures

In a similar vein, we observed significant variability within our sample in regards to the outcome measures and dimensions of

integrated care assessed. These included patient-reported and clinician-evaluated symptom severity,<sup>31,34,37,38</sup> quality of life,<sup>25,31,77</sup> functional independence,<sup>77</sup> caregiver burden such as measured by the Zarit Burden Interview,<sup>25,35</sup> patient, caregiver and clinician satisfaction,<sup>33,35</sup> emergency department visits or hospital admissions,<sup>34</sup> and return on investment.<sup>78</sup> We acknowledge that the idiosyncrasies of neurological disorders demand unique approaches to care, and thus a "one-size-fits-all" approach to the evaluation of program outcomes may not be feasible. However, several outcome measures including quality of life, patient and caregiver satisfaction, healthcare resource utilization and return on investment may be universally assessable across various programs and there already exist validated tools that may be applied to this end, such as the Patients' Assessment of Care for chronic Conditions (PACIC)<sup>75,79</sup> and the Rainbow Model of Integrated Care Measurement Tool.<sup>14-19</sup>

A more harmonized approach to the assessment of outcomes may allow for direct comparisons between programs and for the advancement of the field as a whole, and further research is needed to elucidate optimal methods of evaluation.

### Scalability and sustainability

The care models captured in this narrative review varied considerably in their scale, from local clinics to the redevelopment of national care. The published funding sources of these projects are summarized in Table 1, with many of the smaller scale projects supported by grants and foundations in addition to Medicare funding for clinics based in the United States, while the larger regional and national care models received government and taxpayer funding. Previous groups have called for close collaboration between healthcare administrators and policymakers to ensure that models of integrated care are developed in a realistic and fiscally responsible manner.<sup>80</sup> As many of the initiatives included in this review were in the pre-implementation or pilot stages, moving forward, it will be paramount to evaluate the sustainability and scalability of these models by applying validated instruments such as the B3-Maturity Model (B3-MM)<sup>81</sup> and the Scaling Integrated Care in Context (SCIROCCO) tool,<sup>82</sup> to ensure that resources are used and distributed in a just manner.<sup>81,83</sup>

### The future of integrated care in Canada

In response to growing healthcare challenges globally, Berwick et al introduced the landmark Triple Aim in 2008, focusing on: 1. *Improving the experience of care*; 2. *Improving the health of populations*; and 3. *Reducing per capita costs of health care*.<sup>84</sup> Building on this, Bodenheimer and Sinsky introduced the fourth aim of *improving the work life of health care providers*, to establish the Quadruple Aim.<sup>85</sup> Using the context of the Canadian healthcare system as an example, integrated care offers one such strategy to achieve these aims.

Integrated care focuses on delivering patient-centered individualized care, which may help to provide more equitable care for patients from a variety of socioeconomic and cultural backgrounds than traditional healthcare models.<sup>86,87</sup> Furthermore, by centering around patient autonomy as a core tenet of integrated care, these new models of care carry the potential to contribute to the ongoing decolonization of our healthcare system.<sup>88-90</sup> In addition, several of the discussed care models were co-designed with patient and care partners, allowing for the development of care pathways better suited to serve the unique needs of diverse patient populations.<sup>25,32,41</sup>

In addition, Canada's expansive geography poses unique challenges in the delivery of equitable healthcare services to rural and remote communities.<sup>91</sup> Integrated care models may help to fill this gap as care coordination could improve the accessibility of specialty resources outside of urban centers and offer greater interdisciplinary support to rural family physicians managing complex patients in under-resourced communities, as well as enhance delivery of care to disadvantaged populations, many of whom may have complex multi-domain health care needs and may feel disenfranchised by traditional care models.<sup>24,26,92</sup> Furthermore, the widely increasing adoption of telehealth may serve to increase access to subspecialty care for patients living outside of urban centers who otherwise might need to travel considerable distances to these appointments.<sup>93</sup> In addition, the integration of electronic medical record systems may help to improve communication and the sharing of medical data between clinicians working across different healthcare authorities, which is crucial for care continuity when patients are transferred between hospitals for a higher level of acute neurological care.

Furthermore, early evidence suggests that integrated care may have a positive return on investment with long-term cost savings and therefore has the potential to reduce the financial burden on our healthcare systems while simultaneously providing higher quality patient care.<sup>34,56,78</sup> This is of particular importance in our single-payer healthcare system which has faced growing healthcare costs in recent years.<sup>94</sup> However, future research to better understand the economic impacts of integrated care models is needed, and special consideration should be granted to the challenge of developing reimbursement structures that can adapt to these models.<sup>28,95</sup>

Many of these considerations are by no means exclusive to Canada, and we hope that strong international collaboration will pave the way for the success of applying integrated approaches to healthcare worldwide.

## Conclusion

There is growing momentum in the development of integrated care models for the management of several chronic neurological illnesses. In this narrative review, we summarize current initiatives in integrated care spanning several neurological disorders, including Parkinson's disease, dementia, stroke, MS, epilepsy and TBI. We hope that future work will be established in accordance with universal definitions of integrated care, be applied across a broader range of neurological conditions, and utilize validated outcome measures in order to advance the field of integrated care in a collective manner. Finally, using Canada as an example, we envision the future of integrated care in addressing several challenges faced in our current healthcare system, as well as other healthcare systems globally.

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Dr Rebecca Harrison has received speaking honoraria from Pfizer and EMD Serono and has participated in an advisory board for Servier Canada. She is currently a board member and research committee member with the Brain Tumour Foundation of Canada.

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